

FASD: Knot Alone

Volume 1, Issue 2

Winter 2004

A Quarterly Publication of the SAMHSA Fetal Alcohol Spectrum Disorders Center for Excellence



FASD Center Convenes First-Ever Summit for Women in Recovery

"You are blessed to get treatment. A lot of women don't."

—Woman in recovery who has an adult daughter with fetal alcohol syndrome

Half of all women drink occasionally, and young women drink more than older women. In addition, one in 10 women drinks alcohol while pregnant. Many of these women do not know about the dangers of alcohol use during pregnancy.

Most alcohol treatment centers do not discuss fetal alcohol spectrum disorders (FASD). But that changed in September, when more than 100 women in treatment gathered at the first-ever summit for women in recovery. The SAMHSA FASD Center for Excellence convened the summit for women in treatment, treatment providers, and policymakers.

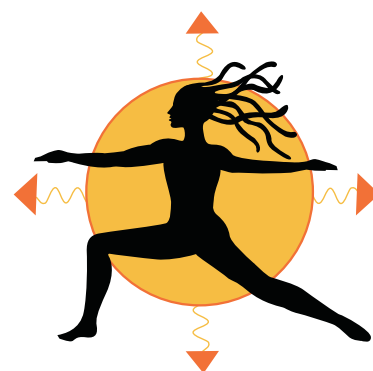
"Hope for Women in Recovery: Understanding and Addressing the Impact of Prenatal Alcohol Exposure" was held in Baltimore, Maryland, September 8 and 9. The meeting was cosponsored by the FASD Center and the National Organization on Fetal Alcohol Syndrome (NOFAS). The summit included:

- Presentations by experts and birth mothers on issues related to FASD
- Family panel on the impact of FASD
- Town Hall meeting
- Session for policymakers to help create the foundation for an FASD State plan in Maryland

The meeting was an innovative approach in that it brought together women in recovery, birth mothers, adoptive parents, treatment providers, and policymakers. These groups seldom meet and rarely have an opportunity to address their issues. Recognizing that some participants might have an emotional reaction to learning about FASD, the meeting planners had counselors available. In addition, the meeting was family friendly—several participants brought their small children.



Birth Mother Network with FASD Center Project Officer Deborah Stone (second from right)



Summit logo

The summit led to the creation of a network of birth mothers of children with FASD. They are holding conference calls, recruiting members, and compiling resources. In addition, the summit helped set the stage for FASD efforts in Maryland. Kumar Barve, majority leader of the Maryland House of Delegates, spoke of the need to devote time and energy to FASD issues. He said that "this is one that we're going to be able to put in the win column."

continued on next page





A highlight of the meeting was Kathy Mitchell sharing her story of addiction and recovery. Mitchell has three grown children, one of whom has FAS. In addition, she had two children who died in infancy, most likely due to prenatal exposure to alcohol. Mitchell eventually received treatment at two different facilities. She went on to get a master's degree and is now the spokesperson for NOFAS. Her remarks were so moving that she received a standing ovation.

FASD Center Steering Committee co-chairs Faye Calhoun and Ed Riley presented statistics and other information about FASD. Dr. Calhoun spoke about the lack of treatment for women and the need to reduce the stigma of alcohol problems. She urged people to talk about alcohol use and to "be your sister's keeper."

Be your sister's keeper.

—Faye Calhoun, FASD Center
Steering Committee Co-Chair

Dr. Riley shared findings regarding the effect of prenatal alcohol exposure on the brain. The audience gasped when he showed a photo of a newborn with FAS. Dr. Riley noted that children with FAS have smaller brains and that the cerebellum appears to be particularly affected. Persons with FAS may also have smaller frontal lobes and basal ganglia. Problems include attention deficits, trouble dealing with complex situations, and deficits in executive functions, such as problem solving.

Julie Gelo, a birth, foster, and adoptive parent of children and adults with FASD, joined Kathy Mitchell in describing the signs and symptoms at various ages. For example, infants may have sleeping and feeding issues, and toddlers may be hyperactive. A panel of birth mothers elaborated on the challenges of raising children with FASD and coping with the guilt so that they did not begin drinking again.

Additional presentations included strategies for families through the lifespan and diagnosis and treatment. After the sessions, a Town Hall meeting was held. Several of the meeting participants testified about their experiences in recovery. They were joined by addiction counselors, family members, and physicians.



Birth mother panel

The second day of the summit was devoted primarily to policy issues. Maryland legislators and State agency representatives shared current efforts in the State related to FASD. They listened to families of individuals with FASD share their struggles, needs, and hopes for the future. The director of the Drug and Alcohol Council praised the summit and noted that Maryland will take the responsibility to follow the lead of other States, such as New Jersey and Minnesota.

More than 100 women in treatment attended the summit. A second summit is planned for the summer of 2004. It will address issues in the Native American community. Full proceedings of "Hope for Women in Recovery" will be available on the FASD Center Web site (fascenter.samhsa.gov).

Steering Committee Sets Tone for the New Year

The FASD Center Steering Committee met in December in Corpus Christi, Texas. They reviewed and approved the Center's strategic plan. They also asked the Center to work with the Interagency Coordinating Committee on Fetal Alcohol Syndrome to map Federal programs and projects related to FASD. This effort will help foster greater collaboration among Federal agencies working on FASD.

The strategic plan helps set the tone and direction of the FASD Center's efforts. It includes vision, mission, and goal statements, as well as objectives and related activities. The Center's vision is to:

1. Reduce the number of cases of FASD.
2. Increase functioning of persons who have FASD.
3. Improve quality of life for individuals and families affected by FASD.

continued on next page



The Center's mission is to facilitate the development and improvement of prevention, treatment, and care systems in the United States by providing national leadership and facilitating collaboration in the field. To carry out its mission, the Center has two strategic goals:

1. Facilitate the development of FASD prevention, treatment, and care as a specialty field.
2. Facilitate the development of FASD prevention, treatment, and care systems at the State and community level.

The Steering Committee discussed ways to advance Center goals, such as approaches to identifying promising and best practices. They also approved an approach to identifying comprehensive systems of care. The approach includes service capacity indicators such as an FASD coordinator, dedicated funding, and service delivery guidelines. In addition, Deborah Cohen, Director, New Jersey Office of Prevention and Mental Retardation and Developmental Disabilities, discussed trends and issues identified at the "Truth and Consequences of FAS" conference in New Jersey.

The Steering Committee is also committed to the Center's efforts to develop high-quality materials and promote consistency in information presented about FASD. Therefore, they asked the Center to develop a basic FASD lecture. An FASD specialist is developing this lecture for posting on the Center's Web site. Center staff are also compiling reading lists for various groups, such as families and caregivers.

The Steering Committee will convene again in spring 2004.

Summer Family Conference Provides New Solutions to Old Problems

One of the challenges of raising children with FASD is finding appropriate group activities. Many children have difficulty in traditional classrooms and camps. Several organizations have found success in developing family-oriented recreational programs. In its ongoing effort to pilot and evaluate innovative intervention strategies, the FASD Center has sponsored two summer family conferences.

The second conference to support children with FASD and their families and caregivers was held at Camp Volasuca in Washington State in August. The FASD Center coordinated the program in cooperation with the Washington State FAS Diagnostic and Prevention Network at the University of Washington. Volunteers of America helped provide onsite support.

The goals of the conference were to provide parent training workshops and respite, activities for children with FASD and their siblings, and family activities. Stone Soup Group of Alaska helped developed the program, based on the family summer camps they have run for the past several years. Stone Soup Group also provided parent training on positive behavioral support, sensory integration, and advocacy.

The children were divided into small groups. Child care was provided for the youngest group. Children ranged in age from 2 weeks to 19 years.

To develop fine and gross motor skills and social skills, youth activities included arts and crafts, field games, campfire activities, songs, and skits. A magician performed, and a carnival night included face painting, games, and prizes. A slumber party was also held with a movie and popcorn.



Field games

Respite activities after parent training sessions included making fleece blankets, receiving a massage, networking, and relaxing. Family activities were designed to provide a relaxed, supportive atmosphere to promote parent networking, informal support, and discussion. Activities included nature walks, scrapbooking, miniature golf, and swimming.

In their evaluations, parents and staff indicated that the program was highly successful. Everyone that attended would come again. The final customer surveys were overwhelmingly positive from the children, parents, and counselors.

continued on next page





One of the most exciting outcomes was the formation of a Parent Mentoring Network. The parents have been corresponding with each other via e-mail sharing questions, comments, and concerns and held a meeting in September. The group plans to meet every month. This group of parents has also agreed to mentor parents of newly diagnosed children or other caregivers dealing with difficult situations.

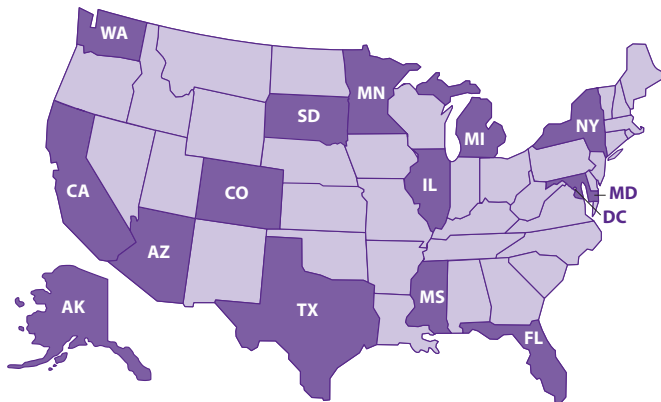
Data from a 3-month followup are currently being analyzed. More details about both summer family conferences will be available in a report from the FASD Center later in the year.

Hundreds Testify at FASD Town Hall Meetings

"I hear over and over from some of the women, 'Well, it's o.k. My doctor said I could have a little drink. It will help me relax.'"

—Nurse

In its first 2 years, the FASD Center for Excellence has convened 15 Town Hall meetings to hear about issues facing individuals and families affected by FASD. Nearly 800 people attended the meetings, and more than 700 individuals provided oral or written testimony. The testimony will inform the Center's work toward preventing and treating FASD.



Town Hall meeting locations

The Town Hall meetings provided a snapshot of how FASD affects the Nation. They spanned the country, from California to New York and from Alaska to Florida. Meetings included special sessions for Native Americans and women in recovery.

Participants included children and adults with FASD, families and caregivers, service providers, researchers, and policymakers. Many cited considerable gaps in services and poignantly described the impact of those gaps on their daily lives. As the voices of parents and individuals with FASD joined with physicians, social workers, and other professionals, distinct patterns emerged.

Two primary needs are respite care and better understanding of FASD by various systems of care, such as education, mental health, and the legal system. In addition, FASD needs to be recognized as a disability so that individuals can receive appropriate diagnoses and services.



At each meeting, a VIP panel of representatives from Federal and State agencies, State legislative bodies, service providers, and the FASD Center listened to testimony. Nearly 200 people participated on VIP panels. Some, such as representatives in Florida and Mississippi, have followed up with additional meetings and training sessions on FASD.

The FASD Center Project Director presented Town Hall meeting findings at two meetings in December: the Interagency Coordinating Committee on Fetal Alcohol Syndrome and the National Task Force on Fetal Alcohol Syndrome/Fetal Alcohol Effect. In addition, all Town Hall meeting testimony will be summarized in a report that will be posted on the FASD Center Web site.

On the Road Again: FASD Center Training Update

It's been a busy time for the FASD Center specialists. In the past few months, they have conducted 35 training sessions for nearly 2,000 participants. Traveling as far as Alaska and Japan, trainers visited 10 States, Washington, DC, and Asia. Dan Dubovsky alone conducted 10 sessions in Hawaii as part of a statewide training effort that reached more than 400 people.

Topics included the FASD Center, FASD 101, Therapeutic Alliances, Loss and Grieving, Adolescents and Adults With FASD, Co-Occurring Disorders, FASD in Education, Identifying Women at Risk, Anger

continued on next page



Management. Participants came from a variety of professions and disciplines, including:

- Case managers
- Certified addictions counselors
- Education professionals
- Health care professionals
- Mental health professionals
- Obstetricians and gynecologists
- Pediatricians

- Public health professionals
- Substance abuse professionals

In addition, families, community members, State systems personnel, policymakers, and women in treatment attended training sessions.

Want to know more? Contact our Information Resource Center at 866-STOP-FAS (786-7327), e-mail fascenter@samhsa.gov, or complete the Training/Technical Assistance Request Form on our Web site, fascenter.samhsa.gov/misc/ttaintro.cfm.



Dear Dan



I think my 4-year-old granddaughter has fetal alcohol effects. I greatly fear for her future. The birth mother is an alcoholic and smoked marijuana while pregnant. My son has custody. This sweet child is having enormous behavior problems, and they are getting worse. There is a newborn and this young family is struggling to cope. We are a large, close family, and we are trying to work together to help this child. She cannot keep friends. To get her way she screams, bites, kicks, etc. I am afraid that during a tantrum, she will hurt herself. At times, she is totally out of control. She talks about how bad she was, apologizes, and becomes a very loving child, until it starts again. Please help.

Nervous Nana

Dear Nervous Nana:

I know it must be difficult for you and your family, but it sounds like your granddaughter will find support and love, regardless of the source of her difficulties. I recommend that she see a trained diagnostician to establish any effects she may have from her prenatal exposure to drugs and alcohol. A proper diagnosis will help you, your family, and others understand her situation, her difficulties and strengths, and the best ways to help her.

Although other disorders may cause the behavior problems you describe, they sound similar to those of fetal alcohol spectrum disorders (FASD). If so, your granddaughter may be acting out in frustration

because she can't express what is bothering her. She could also be overstimulated. Individuals with FASD are often hypersensitive to sensory input and may act out when overwhelmed.

It may help to provide a quiet, uncluttered environment with few toys or decorations. Providing a quiet corner or other place to calm down may also help. But do not lock the child in a room or use a confined area, as this could upset her. You also might want to break tasks down to one step at a time. People with FASD have trouble following multiple instructions, such as "Go to your room, pick up your toys, and put them away." Instead, take her to her room and then ask her to pick up her toys.

These are just a couple ideas. More support is available, such as the National Organization on Fetal Alcohol Syndrome Web-based directory of support groups and other services (www.nofas.org/fasdirect/index.htm), the FAS Community Resource Center (www.come-over.to/FASCRC), FASLink (www.acbr.com/fas/index), and the FASD Center for Excellence Web site (fascenter.samhsa.gov) and toll-free line (866-STOPFAS). Best wishes.

Have a question for Dan?

E-mail fascenter@samhsa.gov and include "Dear Dan" in the subject line. Letters may be edited for content and space. Please indicate whether you want your name and State published.



Letters to the Editor

Nice newsletter! Thanks. I, along with a panel of family members, did a presentation to the Department of Human Services for the Mental Health Division, the Substance Abuse Division, and the Developmental Disability Division. Between the two sessions, approximately 80 people were present. It was wonderfully well received. In spite of the significant budget deficit, reorganization, and all the other day-to-day of the

bureaucracy, they have expressed interest in meeting with me again to further this discussion. I ended my slide presentation with a “Dare To Vision” challenge.

We really have only just begun. Thank you for the “Building FASD State Systems” conference. You gave me the encouragement to move forward.

Joyce Jorgensen
New Hampshire

Editorial Guide

We welcome your thoughts on newsletter topics and other issues. E-mail fascenter@samhsa.gov and include “FASD Center newsletter” in the subject line. Or write to FASD Center Newsletter Editor, 1700 Research Boulevard, Suite 400, Rockville, MD 20850. Include your name, city, and State. Unless otherwise noted, letters may be published with the author’s name and location. Letters may be edited for space and content.

“Name Our Newsletter” Contest Winner Is “FASD: Knot Alone”



Joyce Jorgensen of New Hampshire won the contest. “Knot” refers to the FASD Knot, the symbol of the FASD community. It was inspired by *The Broken Cord* by the late Michael Dorris, who adopted three children with fetal alcohol syndrome.

Dorris wrote that if we ignore children with FASD, they will sink like an elevator with a broken cord. The broken cord may also refer to the umbilical cord, spinal cord, nervous system, or cord between generations. The FASD Knot is a square knot, used to reconnect a broken cord. It was designed by Bonnie Buxton and Brian Philcox of Toronto, Canada, ogradey@pathcom.com.

We appreciate Ms. Jorgensen’s contribution. She will receive a copy of *Daily Affirmations for Forgiving & Moving On*, by Tian Dayton, PhD.

Upcoming Events

FAS Summit 2004: Sustaining Hope, Building Capacity, March 9-10, 2004, Anchorage, Alaska
For more information, contact Department of Health and Social Services, Office of Fetal Alcohol Syndrome, 877-393-2287.

Adults with FASD: Swimming Upstream: A Reality Check, March 24-26, 2004, Vancouver, British Columbia, Canada
For more information, contact Interprofessional Continuing Education, University of British Columbia, 604-822-4835.

Grief and Loss in Addicted Individuals (Dawn Farm Education Series), April 27, 2004, Ypsilanti, Michigan
For more information, contact Karen Echelbarger, Dawn Farm therapist, 734-485-8725.

3rd Annual Full Lives: Quality in Changing Times Direct Support Conference—2004, April 29-30, 2004, Anchorage, Alaska
For more information, contact University of Alaska Anchorage Center for Human Development, 907-272-8270 or 800-243-2199.

39th Annual AHHAP Training Conference: “The Environmental Approach,” June 2-6, 2004, Chicago, Illinois
For more information, contact Association of Halfway House Alcoholism Programs of North America, 480-610-8300 or 800-861-0599.

If you’re pregnant, don’t drink. If you drink, don’t get pregnant.

For more information, visit fascenter.samhsa.gov or call 866-STOPFAS.



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Substance Abuse and Mental Health Services Administration
www.samhsa.gov



SAMHSA
Fetal Alcohol Spectrum Disorders
Center for Excellence

